

EURIM Summary Report

Committee: *Theme 2 - Modernising Government*

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Summary of meeting of the Medical Records Subgroup held in Room 'O', Portcullis House, Westminster, Wednesday 20 November 2002, 1000 – 1200. Chair - Geoff Llewellyn (Schlumberger-Sema)

1. Objectives

1.1 The objectives of the meeting were to:

- revise the draft document and produce firm recommendations in an appropriate format;
- use the final document to help change the nature and balance of the current debate on privacy and data sharing, in the context of the PIU consultation.

2. Setting the scene

2.1 In order to help bring about the required changes in thinking and culture in the NHS, we should aim to brief Parliamentarians from the perspective of NHS professionals who are fully acquainted with how the system works. We should therefore hold a series of small group sessions with senior health care professionals and MP's to address the issues involved.

2.2 Medical Records as an issue was a top political priority now, but big questions that need a solution remain, e.g.

- **managerial problems of how to get staff to use the technology available;**
- **how to adopt a universal coding system.**

2.2.1 There was a need to overcome institutionalised obstruction to data transfer systems. GP's had started to use IT, but use by other health care professionals (HCP's) was patchy, e.g. the Royal College of Orthopaedics believed it should require members to maintain type-written (usually word processed) notes, rather than accepting hand-written records. **The group should emphasise the need for cultural change at all levels in the NHS as an urgent priority.** The current disorganised policy on IT was now moving strongly towards a central NHSIA policy responsible for national development, co-ordinated with other systems. 100% of consultants now have computers on their desks, though connectivity and willingness to use was still an issue. GP's are generally further ahead in use of IT and with NHS Net can talk to each other, but not exchange patient data. Although GP's are comfortable with IT, hospitals seemed to present a real barrier, and new users of systems, such as consultants, would need incentives. Progress in other areas related to data handling was being made – every baby is now given a unique identifier at birth.

2.2.2 The NHS is moving towards adopting SNOMED (Systematized Nomenclature of Medicine) as the official standard clinical coding classification and terminology. SNOMED CT is currently being evaluated by the NHS Information Authority, which has made a substantial investment in the development of the terminology. A final decision on whether SNOMED will become the mandated standard clinical terminology for the NHS is now promised once the NHSIA has completed its evaluation early in 2003.

2.3 Ministerial priorities were now focusing on equity and social justice rather than simply efficiency.

3. Revising the draft Working Group document

3.1 It was agreed that there was no technological challenge to data sharing in medical records; the main obstacles were cultural and managerial. The group should therefore focus on recommendations for cultural change. There were 2 contrasting approaches to the procurement and widespread adoption and use of IT systems in preference to paper records:

- A big bang' approach - lessons should be learned from previous large-scale IT disasters;
 - A stepwise approach, beginning with e.g. pilots in prescribing and moving into other areas. The value of pilot projects was in showing that particular operations were 'do-able'.
- 3.2 A prerequisite for any pilot system (large or small) is that it must be capable of replication and be joined-up – interoperability is key! The benefit of a stepwise approach to the end-user should be emphasised. Electronic and paper records should only co-exist during transition to full digital data systems, but a precondition for digital data input was that it must be easier for the operative than paper records. The switch to digital data would come only when all pre-conditions for confidence in success had been met.
- 3.3 The document should engage with current developments within the NHS, e.g. the code of practice on the strategy for e-records.
- 3.3** The document should be patient-centric – if patients didn't trust the system, the attitudes and practices of health care professionals, and the investment in systems, were irrelevant – it simply wouldn't happen. A previous conference had highlighted the level of patient distrust of data sharing. Moreover, we should recognise that records will continue to be held in paper form for many years, if only because of the cost of loading back data. The public climate was suspicious, and fed by media headlines about potential abuses of power by 'data controllers'. All safeguards therefore needed to be clear and explicit. **The document should exploit the findings of the MORI poll as a means of highlighting public confidence in data sharing within the NHS.**
- 3.4 the draft document should:**
- **emphasize patient benefit of data sharing in healthcare;**
 - **propose the use of a generic permissions form;**
 - **highlight the fact that technical issues are subordinate to political, managerial and cultural problems;**
 - **make reference only to potential problems of requests for data sharing from non-NHS bodies;**
 - **state the need to define the boundaries of the NHS and/or of Health Care Professionals;**
 - **propose seamless transition in data sharing between NHS and private healthcare;**
 - **link to the NHSIA consultation document;**
 - **interact and refer to with current developments in the NHS.**

Recommendations should also be tilted toward more exploration of the issues with appropriate workshops rather than moving immediately to hard recommendations.

4. Patient perspectives

- 4.1 A common complaint was that patients had to give the same information time and again to different health care professionals. Permissions for data sharing should be obtained from a patient where possible at a non-stressful time, perhaps backed up by an information leaflet: PIAG were already looking at this. Such data would have to be updated as individual circumstances change.
- 4.2 Patients need to know why they are giving this information and what risks are associated with electronic and paper data. We should emphasize the fact that with the appropriate mitigations and safeguards, e-systems are actually safer than paper. **The overarching priority was that data would only be used for patient benefit, and anonymized for statistical use.**
- 4.3 Patients were most concerned with the *quality* of their records, rather than just consent and confidentiality.
- 4.4 The group should link in to the current NHSIA consultation and identify relevant areas of debate. Most people are unaware of this, or where to go for associated documentation. We should therefore organize workshops for different health care professionals and other interested people, and identify the issues people should be responding to.

- 4.5 We should also engage with the NHS information strategy: the Nuffield Trust would be reporting the results of their research later this month.
- 4.6 It was important to follow guidance from the Information Commissioner on the issues of consent and the sharing of medical data. We should clarify the fact that there are different permissions for different purposes, perhaps by using patient scenarios.
- 4.7 Other questions to be resolved included:
- the need for guidance and routines when healthcare boundaries are crossed;
 - the need for boundary policing;
 - the need for an authoritative and proactive advisory service for policing boundaries;
 - patients access to their own digital medical data;
 - carers rights and responsibilities regarding privacy and data sharing (especially when they are the interface for an individual with communications or mobility difficulties);
 - the need for interoperable systems.

5. Future action

5.1 Looking beyond the draft document, the subgroup would need to organize a series of exercises to discuss and/or investigate technical and operational procedures for knowledge management solutions, before making recommendations. These might include workshops on ethical, legal and moral issues, the possible need for a central index of permissions, patient access to their own records and the policing of data sharing. Workshops should be held in parallel with current consultations.

5.2 The resulting brief must be attractive to look at and read, contain a succinct 'vision' and 'soundbites' that will hook the interest of MP's, attract political attention, be patient-centric, and focus on current issues and priorities.

5.3 Outcomes should be planned for Spring 2003 to coincide with decisions on the IT transformation programme. It was planned to finalise the current draft and distribute it as a draft for discussion to target audiences before Christmas, 2002.